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Care homes as hospices for the prevalent form of dying: An analysis of long-term care provision towards the end of life in England

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Highlights

1. In England, most people die aged ≥80 from dementia or chronic diseases.
2. However, little is known about what determines LTC and EOLC arrangements in old age.
3. Care homes cater for the prevalent form of dying (aged ≥80, with dementia).
4. Dementia and Parkinson's disease are the strongest determinants of high formal LTC.
5. Reliance on informal family care more than already done is not sustainable.

Abstract

In the UK and the Westernised countries, most people die aged 80+ from disabling, chronic and degenerative diseases, having spent several years in poor health. There is thus continuity between long-term care (LTC) and end of life care (EOLC) in old age, but this continuity is poorly understood within policy and almost nothing is known about what determines the modality and intensity of LTC provision in old age towards the end of life. Drawing on multinomial logistic regression analysis of the English Longitudinal Study of Ageing (ELSA),

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this paper evaluates how health and socio-demographic factors affect the relative probability of receiving care through one of five long-term care arrangements (LTCAs) from the time of need at age ≥50 to death; and assesses the consequences this has for the English LTC and EOLC policy and planning. The study reveals that hospices provide end-of-life LTC for cancer diagnoses and adults aged 50-64, while care homes provide open-ended and end-of-life LTC for non-cancer diagnoses, dementia, severe disability, and adults aged 80+. Further, the informal, formal, mixed and care home LTCAs reflect increasing levels of disability and ill-health, and decreasing levels of family support, with differences concerning education and gender. Finally, dementia and Parkinson's disease are the single strongest determinants of high formal LTC provision, and overall high care needs determine high formal LTC provision. Within the English context, the consequences of this are that: 1) Continued reliance on informal family care is not sustainable; 2) To provide free formal LTC to old adults with high care needs is appropriate; and 3) Hospices do not cater for the prevalent form of dying in old age while care homes do, being the *de facto* hospices for severely disabled, very old (80+) adults with dementia. Yet this is not represented in English EOLC policy and research.

Keywords

Care Home; Class differences; Dementia; End of life care; England; Gender differences; Long term care; Old age; Palliative care; Parkinson's disease; Residential aged care; Social Care; Social care policy, UK.

Introduction

In Western, industrialized societies, dying now happens overwhelmingly in very old age, when the risk of functional dependency and protracted dying is higher. This paper investigates the patterns of long-term care (LTC) *and* end of life care (EOLC) provision in old age, thus

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contributing to the fields of ageing *and* palliative/EOLC. As already noted in the pages of this journal, ageing and palliative care are established fields, while their interplay remains under-researched (Gott et al., 2008), especially through quantitative methods. Of the quantitative accounts that do exist on the patterns of social care in old age, they do not include key health predictors (chronic diseases) and they do not address dying, institutional nor hospice care, in a time of global population ageing and protracted dying (Solé-Auró and Crimmins, 2014). Of the quantitative accounts that exist on place of death, the focus is on the last year of life. What is more, they do not identify whether and how LTC was provided at home, and exclude hospices (Fleming et al., 2010; Houttekier et al., 2009) or focus only on institutional care (Connoly et al., 2014).

This study adopts a macro-level, long-term, and objective epistemological standpoint on EOLC. It defines EOLC as care that occurs *towards* and *at* the end of a long life, thus linking it to continuing patterns of LTC provision (Table 1). Applying multinomial logistic regression analysis to data from the English Longitudinal Study of Ageing (ELSA), this study estimates the relative probability that adults in receipt of social care from the time of need at age ≥50 to death had to be in one of the five possible LTC arrangements towards the EOL (Table 2), based on a number of health and socio-demographic predictors (Table 3). The LTC arrangements were *objectively also* EOLC arrangements since all respondents were observed receiving care at the time of dying, that is in the last three months of life.

With most studies on LTC characterising it as a somewhat disconnected period of life that does not extend towards death, the focus on continuing patterns of LTC *until* death is what makes this study unique. In England, over half of the very old die in a residential setting with 37.6% of those aged 85+ dying in a care home and 16.7% dying at home (PHE, 2018). Conversely, only 42.8% die in hospital (Ibid.), spending only five days there on average (Ewbank et al., 2017). Therefore, in England, LTC in residential settings, be they an

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institutional one or a private home, informs EOLC in old age to a larger extent that LTC in hospital. The situation is very similar in Belgium, Iceland, Canada, and Australia, and is the same in the US and New Zealand where respectively just under 50% and well over 50% of the over-65s die in residential settings as opposed to hospital ones (Broad et al., 2013).

In line with the Barker Commission on the Future of Health and Social Care in England (Brown and Barker, 2014), the findings support the claim that the social and health care systems need to undergo significant transformation to meet the high care needs of some older people and the families supporting them. 74% of adults in the study receive care from a relative (Table 2); at a time when dementia, which the study reveals is the single strongest predictor of institutional care, is the leading cause of death in the UK (ONS, 2019), and the number of highly dependent English adults is expected to increase by 36% in the over-65s and to almost double in the over-85s by 2035 (Kingston et al., 2018). The study further reveals that care homes are becoming the *de facto* hospices for severely impaired, very old (80+) adults, affected in particular by dementia, Parkinson's disease, and stroke; yet there remains a lack of an English national strategy addressing EOLC in care homes. As both New Zealand and Australia implemented significant policy initiatives to address dying in care homes; are global leaders in the provision of quality EOLC together with the UK (EIU, 2015); feature among the highest proportion of care home deaths worldwide at 38% and 32% respectively (Broad et al., 2013); and feature Alzheimer's disease in the top three leading causes of death (together with the US, Canada and most European countries) (IHME, 2017), they will be taken as benchmarks for international comparison throughout the paper.

The first section of the paper contextualises dying in old age within the English EOLC and LTC policy framework, using New Zealand and Australia as international comparators, and thus providing a rationale for the study. The second section defines the study's design, scope, limitations and statistical methods. The third section reports all the study's results. The

fourth section evidences the study's key findings in relation to the English social and health care systems organisation as well as comparable findings from the international literature. The final section discusses the findings' implications for social and health care policy, with a focus on LTC and EOLC in old age within the English national and international context.

1. Long-Term Care and End of Life Care in England

1.1. Dying in old age

In the UK, most people die aged 80+ from disabling, chronic and degenerative diseases, having spent an average of nine years in poor health (ONS, 2018a, 2018b, 2016). Death is increasingly experienced at the end of long, fluctuating trajectories of ill health and functional decline, and dying itself can cover many months or years (Murray and Sheikh, 2008). The end of life has thus become, for most people, a protracted period of time shaped by the unpredictable trajectories of dying of the two most common disease groups in old age: (i) frailty and dementia (dwindling dying), and (ii) chronic heart and lung diseases (intermittent dying) (Murray and Sheikh, 2008; ONS, 2016). Dwindling dying implies gradual decline with high, but fluctuating disability levels. Intermittent dying implies a series of acute episodes resulting in partial recovery or death. With cancer deaths remaining prevalent in younger age groups (35-79 y/o) and displaying more linear trajectories of dying, lasting only a few weeks or months (Ibid.), the continuity between LTC and EOLC in old age is poorly understood in policy, and does not fit well within the English social and health care system.

English EOLC policy and services remain cancer and middle age centered (Borgstrom, 2016). Evidence of this are the disproportionate resourcing of hospices vis-à-vis care homes (see section 1.2), the differential access to specialist palliative care services (SPCSs) based on diagnosis and age (see section 4.1), and that policy defines the EOL as the last year of life,

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although the prognosis of an accurate timeframe for dying, especially for non-cancer diagnoses, remains practically impossible (Teggi, 2018). Further, the main providers of formal LTC for older adults as well as their informal carers and advocates are failing to feed into the national EOLC debate. Care home and homecare providers as well as older people's advocacy groups, even though acknowledged, are still mostly marginalized in EOLC policy debate, which is dominated by hospices and SPCSs (see DoH, 2016). This is perpetuated by the lack of a government-funded national programme addressing death and dying in care homes. In light of this, the protracted trajectories of dying in old age, and the disconnect between LTC and EOLC in policy and research practice, the study adopted a long-term framework for the EOL, extending it well beyond the one year before death arbitrarily set by the English EOLC policy (Table 1).

The situation is different in New Zealand and Australia, with integrated planning across different settings. The latest New Zealand palliative care action plan was designed in close collaboration with the aged care and care home sector (MoH, 2017). The latest Australian EOLC policy (AGDoH, 2018) stresses that palliative care is available in almost every healthcare setting, care homes included. Although not immune from instances of neglect (Royal Commission, 2019), such an approach is the result of significant government investments in research and clinical education since the 1990s. In Australia, the federally funded Making Health Choices (MHC) developed, trialled and evaluated a system for implementing advance care planning in care homes across the country (Silvester et al., 2013). This is a far cry from the English context in which the only national training programme for EOLC in care homes, the Gold Standards Framework, is a grassroot initiative available only to self-funding providers (GSF, 2020).

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1.2. The organisation of LTC provision

Social LTC provision in England is almost entirely private. Institutional care is mostly provided by profit (76%) and not-for-profit (11%) suppliers (Laing & Buisson, 2018), while 92.1% of local authority-funded homecare is provided by the independent sector (UKHCA, 2016). Eligibility criteria for social care are strictly needs- and means- tested. Due to austerity measures and local authority budget cuts reducing the number of publicly-funded care recipients, unmet need has increased by almost 20% in 2016-2018, meaning that 1.4 million people were not receiving all the help they needed in 2018 (Age UK, 2018). Further, local authority funding does not meet providers' costs, producing an unstable and failure-prone market in which self-funders offset the deficit by paying on average 41% more for the same services (Humphries et al., 2016). NHS Continuing Healthcare is the only case in which all (social and health) care is supplied for free under an NHS budget. However, it is accessible only to people with extremely high healthcare needs and only after a long and disputed assessment process (Oliver, 2016).

As the Barker Commission acknowledged, the health and social care divide produces inequalities in care provision in old age depending on diagnosis (Brown and Barker, 2014). While the NHS is free at the point of need, social care is heavily needs- and means-tested. Such provision does not map neatly onto the needs of functionally and/or cognitively impaired old people who require both health and social care. As my study evidences, older adults received help with the activities of daily living (ADLs) from both healthcare and social care workers both at home and in institutional or hospice settings (Table 2). This further suggests that dying from cancer tends to be freely provided for under the NHS and hospice sector, funded at third by the government (Hospice UK, 2016a), while dying from dementia and Parkinson's disease tends to be completely or partially paid for by individuals. People with conditions that can involve very similar care workloads and needs will thus contribute towards the cost of their

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care very differently. On this basis, the Commission called for an alignment in entitlements for health and social care implying all care (except accommodation costs) becoming free at high levels of need, to which an alignment in funding and commissioning should correspond.

To date, English LTC and EOLC provision are thus inequitable, scarcely integrated with the healthcare system, and heavily reliant on informal care to meet demand; the economic value of family care exceeding that of paid care by several times (Hoff, 2015). Given this, in terms of projections and planning, a study to predict the modality and intensity of LTC provision in old age towards the EOL in England was overdue, including not just health and demographic factors, but also social factors such as income and the availability of family support.

Internationally, the study remains both original and relevant as it expands the international literature on place of death (see Connoly et al., 2014; Fleming et al., 2010; Houttekier et al., 2009) by analysing the modality of LTC provision in a country which shares the global trends towards increased home and care home deaths in old age (Broad et al., 2013) as well as increased deaths from dementia (IHME, 2017). It also reflects the UK's position at the forefront of developing integrated and comprehensive EOLC provision together with New Zealand and Australia (EIU, 2015).

2. Method

2.1. Design, scope and limitations

This study examined how a number of demographic, health and social predictors affected the relative likelihood of receiving care through *one* of five LTC arrangements (LTCAs) in old age towards the EOL. To do so, multinomial logistic regression analysis of the ELSA core waves 2-5 and EOL waves 2-4 and 6 was performed, including only those respondents receiving help with at least one ADL - that is receiving social care - from the time of need at

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age ≥50 to death (Fig. 1). The core waves, collected every two years during 2005-2013, are multi-dimensional surveys targeting a respondent's lifetime. The EOL waves are a much-reduced version of the core waves targeting a respondent's last year of life via proxy-interviews with the bereaved. Core wave 1 could not be used as it excluded institutional respondents. EOL wave 1 and 5 were not collected. To use the full potential of the ELSA, representative of the English population aged ≥50, age 50 was adopted as the threshold to define old age within this study.

The merging of two different waves, the core and the EOL, permitted the analysis of care patterns *over the last years of life until death* as opposed to exclusively at the point of death or in old age, and to include *a number of health and social predictors* as opposed to solely age or disability-related and living arrangements ones (excluding chronic diseases), as has been the norm to date (Fleming et al., 2010; Solé-Auró and Crimmins, 2014). This enabled us to isolate and compare the unique impact each predictor had on the occurrence of a LTCA over the others. It also allowed us to include as rich a set of controls as possible to address potential sources of bias, based on observables (Table 3).

The dependent variable (DV) (Table 2) was obtained combining the variables for institutional respondents and who helped with the ADLs from both waves and the Institute of Fiscal Studies (IFS) derived variables datasets. Hospice featured only as place of death in the EOL waves. It was included as an average hospice stay in the UK lasts only 15 days (Hospice UK, 2016b. England level data unavailable). Most respondents still received care from relatives while residing in a care home or hospice. While this evidences family relations of care continuing into institutional and hospice care (Borgstrom et al., 2019), multinomial logistic regression analysis required only one observation to be assigned to only one pattern, so priority was given to the 24/7 care provider.

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The merging of two different waves posed also some limitations. Income displayed missing values on all EOL waves as it originated from the IFS datasets, derived from the core waves. These were replaced using the respondent's last observation before death from the core wave. Replaced observations thus dated on average two years before the year they came to represent. Income values were inflated to 2018 £s using the CPI and appropriately deflated when replacing the missing values on the EOL waves. Two other IVs, arguably less time-sensitive than the former, were replaced in the same way: number of adult children and cohabiting adult child.

2.2. Statistical methods

The recoded dataset comprised 1,296 observations with 21 missing data points (1.62%). However, Little's test was significant (χ^2=139.557, DF=84, p=0.000). Therefore, data missing completely at random (MCAR) could not be inferred. Since no single method can satisfactorily deal with non-MCAR data, two statistical methods to tackle missingness were applied: listwise deletion and hot-deck imputation with random sampling from donor observations. The two approaches delivered consistent multinomial logistic regression estimates, which were thus deemed robust. The multinomial logit regression models specified that standard errors allowed for intragroup correlation (between unique respondents across waves) and were formulated as follows:

$$\Pr(y_i = j) = \frac{\exp(X_i \cdot \beta_{ij})}{\sum_{k=1}^{4} \exp(X_i \cdot \beta_{ik})}$$

In which yi represents the LTCA of individual i, with j taking five values: informal care at home; formal care at home; mixed formal and informal care at home; care home; and

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hospice. Xi is the vector of individual characteristics, with β_{ij} and β_{ik} vectors of coefficients. Average marginal effects (AMEs) were computed only for the multinomial logit model fitted on the listwise deletion dataset, which delivered a final dataset of 1,275 observations and 793 unique respondents. AMEs were computed for each outcome, that is for each value of the DV. In non-linear probability models, AMEs are better estimates of partial effects than regression coefficients. They are the average of the marginal effects computed at every value of the IV, holding all other IVs constant. Therefore, AMEs are optimal summary estimates of each IV's unique impact on the likelihoods that one LTCA (that is one value of the DV) was provided over the others (that is the other values of the DV).

The main assumption underlying multinomial logistic regression analysis is the independence of irrelevant alternatives (IIA). The IIA states that the odds of preferring one of two values of the DV does not depend on the presence or absence of a third alternative. In this context, the IIA means, for example, that the relative odds of choosing informal over hospice care are not affected by the presence or absence of institutional care as an option. The IIA assumption is a strong assumption in most empirical applications. However, given the differences between the modalities of care – they are not perfect substitutes for each other, with many implications of the choice – it seems reasonable to assume that in many cases the choice between any two options is not affected by the presence or absence of a third.

3. Results

The multinomial logit model showed sufficient predictive power [Log-pseudolikelihood= -1306.4762 Pseudo R^2= 0.221, $p>\chi^2$= 0.000] and was a good enough fit to the data [Hosmer-Lemeshow test for mlogit: $\chi^2(32)=28.461$, $p>\chi^2=0.646$]. Based on the AMEs in Table 4, we report the significant predictors' partial effects.

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3.1. Informal Care at Home

On average, male older adults were 7.8 percentage points (ppts) more likely than females to receive informal care at home as opposed to other LTCAs. Likewise, old adults aged 50-64 and 65-79 y/o were both 9.3ppts more likely than adults aged 80+ to be attended exclusively by relatives at home, rather than other LTCAs. Old adults with light and mild (rather than severe) disability were respectively 28ppts and 15.3ppts more likely to live at home with the help of a relative, rather than in other LTCAs.

Old adults with a diagnosis of cancer, heart condition and dementia were respectively 12.3ppts, 13ppts and 16.7ppts less likely to be supported informally at home, rather than other LTCAs. Moreover, adults with Parkinson's disease were 19ppts more likely to receive informal homecare rather than other LTCAs.

Living with a partner and adult child predicted respectively 14.6ppts and 20ppts increase in the likelihoods of informal homecare as opposed to other LTCAs. Those with two and 3+ children were respectively 7.6 and 11.4ppts more likely to be in informal care at home than other LTCAs compared with those with no children.

Finally, old adults who attained less than O-level as opposed to A-level+ are 12.6ppts more likely to be in informal care rather than other LTCAs.

3.2. Formal Care at Home

Female old adults were 4.1ppts more likely than males to receive homecare provided exclusively by a paid carer as opposed to other LTCAs. Further, low disability predicted formal care at home with a 3.9ppts increase (with respect to the other LTCAs). On the contrary, a diagnosis of Parkinson's disease diminished the likelihood of being cared for formally at home

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by 58.9ppts (with respect to the other LTCAs); and so did a diagnosis of multimorbidity, albeit by only 5ppts.

Those with a cohabiting partner and adult child were respectively 3.5 and 5.9ppts less likely to be in formal homecare than other LTCAs. Finally, old adults with two and 3+ adult children as opposed to none were respectively 4.6 and 5.8ppts less likely to be receiving formal care at home (as opposed to other LTCAs).

3.3. Mixed Formal and Informal Care at Home

Light (as opposed to severe) disability predicted a 13.1ppts decrease in the likelihoods of receiving both paid and unpaid LTC at home (rather than other LTCAs). In contrast, to have Parkinson's disease and a heart condition predicted respectively a 55.8ppts and 11.6ppts increase in the probability of mixed homecare (over other LTCAs).

Moreover, those with a cohabiting child were 16.1ppts less likely and those with only one child (as compared to none) were 9.7ppts more likely to receive mixed homecare than other LTCAs. Finally, old adults who attained less than O-levels as opposed to A-levels+ were 6.9ppts more likely to receive mixed LTCA (as opposed to other LTCAs).

3.4. Care Home

Adults aged 50-64 and 65-79 y/o were respectively 11.4ppts and 5.3ppts less likely than adults aged 80+ to be looked after in a care home as opposed to other LTCAs. Low and medium (as opposed to severe) disability predicted respectively a 17.2ppts and 10.4ppts decrease in the likelihoods of institutional care.

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Old adults with dementia were 20ppts more likely to live in a care home as opposed to other LTCAs. Old adults with Parkinson's disease (+31.1ppts), arthritis (+8.1ppts) or who have suffered from a stroke (+8.3ppts) were more likely to be in care homes, as opposed to other LTCAs. Conversely, a one unit increase in the total number of chronic illnesses (that is one more illness) predicted a 4.5ppts decrease in the likelihoods of institutional care (over other LTCAs).

Finally, old adults who were single or bereaved were 7.2ppts more likely to be in a care home than in other LTCAs. Similarly, old adults with one, two and three or more children as opposed to none were 11.7ppts, 12.5ppts and 10.3ppts less likely to be in a care home (as opposed to other LTCAs).

3.5. Hospice

Adults aged 50-64 y/o were 3.7ppts more likely than adults aged 80+ to spend the end of their lives in a hospice (rather than other LTCAs). Old adults affected by Parkinson's disease (-47.2ppts), chronic obstructive pulmonary disease (COPD) (-4.2ppts), or a heart condition (-6.8ppts), were less likely to be dying in a hospice, but those affected by cancer were more likely to die in a hospice rather than other LTCAs (+12.3ppts). A one unit increase in the total number of chronic illnesses predicted a 1.9ppts growth in the likelihoods of hospice care (over other LTCAs).

4. Principal Findings

The results revealed four key findings:

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i. Hospices are 'shorter-term' LTC settings specialising in EOLC for cancer diagnoses and adults aged 50-64.

ii. The informal, formal, mixed and care home arrangements reflect increasing levels of functional disability and ill-health, and decreasing levels of family support. Domiciliary LTC provision is differentiated along the axes of class and gender, with poor education and being a man predicting informal homecare, good education predicting mixed homecare, and being a woman predicting formal homecare.

iii. Dementia and Parkinson's disease are the single strongest predictors of high formal LTC provision.

iv. High care needs determine high formal LTC provision.

Each of these findings will be dealt with in turn. The fact that income did not significantly influence the choice of a LTCA might be due to the effectiveness of needs- and means-testing to access appropriate local authority-funded LTC or the limitations outlined in section 2.1, which could have downplayed the impact of high income on access to paid LTC. Further studies are needed to asses this.

4.1. Hospices

As expected, hospices were the only LTCAs active only when dying, that is in the last three months of life (Table 5). Old adults with a non-cancer diagnosis - that is Parkinson's disease, COPD, and a heart condition - were unlikely to receive hospice care (Fig. 3). Conversely, old adults dying with cancer were most likely to be in receipt (Fig. 3). Further, hospices were more likely to cater for the youngest (50-64 y/o) as opposed to the oldest (80+

y/o) old adults (Fig. 2). This is consistent with the fact that dementia, heart conditions and COPD, rather than cancer, are in the top five leading causes of death for adults aged 80+ (ONS, 2016). Hence, hospices configure themselves as 'shorter-term' LTC settings specialising in oncological terminal care. Conversely, care homes configure themselves as both open-ended and end-of-life LTCAs providing for very old (80+), very disabled adults with dementia and other non-cancer diagnosis (Table 5, Fig. 2).

This study confirms the wealth of evidence showing that, in England, cancer (associated with younger old age) remains the primary determinant of access to hospice and SPCSs, while other advanced life-threatening conditions of comparable symptom burden (heart conditions and COPD) have poor access (Dixon et al., 2015). The unpredictability of non-cancer trajectories (intermittent or dwindling) as opposed to the relative predictability of cancer ones is reported as the main reasons why SPCSs are less likely to cater for non-cancer patient (Ibid.), and relatives are more likely to expect cancer deaths than deaths at age 80+ (Teggi, 2018), thereby evidencing a bias for providing cancer rather than old age EOLC.

The situation is very different in the US where noncancer diagnosis results in equal access thanks to a six-month prognosis criterion to receive hospice care (Johnson et al., 2007).

4.2. High care needs, low family support, education and gender

The informal, formal, mixed and care home arrangements reflect increasing levels of functional disability (Fig. 2), ill-health (Fig. 3), and age (to a lesser extent, Fig. 2) as well as decreasing levels of family support (Fig. 4). Hospices will not be considered in this and following analyses since they hold a markedly different position in the economy of dying in old age as shown in the first finding.

Care homes attend to those old people with the highest social and health care needs (most likely to be severely disabled, aged 80+; have dementia, stroke and arthritis, but lower

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comorbidity rates) and the lowest family support available (most likely to be childless, single or bereaved). Inversely, informal LTC at home addresses old adults with the lowest care needs (most likely to be only lightly or mildly disabled, aged below 80, free from dementia, cancer, heart conditions and arthritis, but likely to have Parkinson's disease) and the highest family support available (most likely to have a cohabiting child, a cohabiting spouse/partner, and three or more children). In between the two extremes, mixed homecare mainly supports those adults with medium-high care needs (most likely to have Parkinson's disease and heart conditions, unlikely to be lightly disabled) and some family support available (most unlikely to cohabit with their adult child, but likely to have one). While formal homecare mainly supports those old adults with little care needs (most likely to be free from Parkinson's disease, likely to be lightly disabled) and little family support available (unlikely to have a cohabiting child, a cohabiting spouse/partner, and two or more children).

Although not decisive, the availability of family helpers remains an enabling factor for care in a domiciliary context, especially in the presence of Parkinson's disease (see third finding). Therefore, if we take education as a proxy for class and assume heterosexual marriage/partnership to be the norm for this cohort, the burden of informal, unpaid care appears to be distributed according to class and sexual hierarchies - the first having a stronger impact than the former. Low education positively predicts informal homecare while it negatively predicts mixed homecare. This is in line with the finding that, in England, provision of extensive spousal care (20+ hours/week) is prevalent among those with lower levels of education, while lighter spousal care (1-19 hours/week) is prevalent among those with higher-level qualifications (Young et al., 2006). In the West, working-class household members are in fact more likely to experience disabling work injuries and have limited financial and social resources to access paid care (Anttonen and Zechner, 2011). No such differences were found with respect to institutional care in this study, but in Brussels people residing in community

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with a high socioeconomic status (SES) were almost twice as likely to die in care homes compared with people from low SES communities (Houttekier et al., 2009).

As regards gender, older men are more likely to receive informal homecare than older women, with women more likely to receive formal homecare. Given that spouses provide just under half of informal aged care in England (Hoff, 2015) and that extensive spousal care is higher among English women (Young et al., 2006), this reflects women surviving their husbands as much as gendered expectations - and associated segregation of knowledge - about care responsibility and expertise within heterosexual households in Western culture (Anttonen and Zechner, 2011). Moreover, considering that adult children provide just over half of informal aged care in England (Hoff, 2015) and that having no adult children (as opposed to two or more) predicts informal homecare, women's higher likelihood to receive formal homecare appears related to their prevalence among childless respondents in the study sample (57.47%). Hence, childless older women emerge as the category most likely to access formal homecare, at times *after* having cared for their deceased husbands.

4.3. Neurodegenerative diseases

Parkinson's disease was by far the single strongest determinant of LTC provision. Among chronic diseases, dementia was the second strongest determinant. Both conditions were most strongly associated with one of the two formal LTCAs capable of providing more hours of care a day, paid homecare alone providing only a few hours of care a day (UKHCA, 2016). This accounts for the very high impact Parkinson's disease and dementia have on the overall need for supervision and care, independently of disability level, other chronic conditions and family support available.

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In line with this, unaided family carers were likely to support old adults with Parkinson's disease while paid domiciliary carers were not, unless aided by families as in the mixed LTCA. This might well relate to the fact that cohabiting spouses deliver just under half of informal aged care in England (Hoff, 2015), with their being able to provide more hours of supervision and care a day. Further, care homes were only 10ppts more likely than informal homecare to support old adults with Parkinson's disease (Fig. 3). This suggests that Parkinson's disease can be handled at home with the (exclusive or inclusive) involvement of family carers, the crucial factor being virtually 24/7 supervision and care.

In contrast, dementia was unlikely to be supported at home by informal carers only, while it was the single strongest predictor of care home provision. This signals that dementia is a more demanding condition than Parkinson's disease, requiring not only virtually 24/7 supervision and care, but one which is also very challenging for family carers. Old adults with dementia are in fact over-represented in the English care home population (NDIN, 2016), and the international literature reports that caregivers' risk of depression is higher when caring for old adults with dementia as opposed to any other chronic condition, caregivers' depression remaining the main cause of the premature termination of homecare (Schoenmakers et al., 2010).

4.4. High care needs determine high formal LTC provision

Health and demographic factors determine LTC provision to a larger extent than the availability of family support. Comparing the AMEs from the highest- to the lowest-scoring, disability levels, chronic diseases and age (Fig. 2-3) had a higher impact than cohabiting with an adult child, a partner, and the number of adult children (Fig. 4). This remained true even when excluding Parkinson's disease, which was the single largest predictor. Therefore, LTC

provision towards the EOL depends primarily on the older adults' social and health care needs, rather than the presence of relatives as caregivers.

This provides a strong case for the necessity of mixed domiciliary or institutional LTC when care needs are respectively medium-high and very high. Arguably, the provision of both formal and informal homecare can cover more hours a day than either one of them alone. Further, a paid home carer can relieve the informal carer's workload, thus helping them sustain the caregiving effort long-term. On the other hand, care homes remain the preferred solution when dementia and high functional impairment arise. This suggests that English families are unable to absorb the medium-high and very high care needs of older relatives unaided, thus requiring partial or total formal support.

5. Conclusions and Implications for Policy

Concurring with the Barker Commission, the findings confirm that the English social and healthcare services need to undergo significant transformation to respond to the needs of some older adults and their families. The study found that high care needs require some form of formal LTC support, be it institutional or mixed domiciliary. Since care needs in the over-85s are set to increase (Kingston et al., 2018), as are deaths from dementia (ONS, 2019) - associated with care home provision - the findings evidence that, in the English context, to rely on family care more than already done is not sustainable.

As part of the new settlement for health and social care, the Barker Commission proposes a graduated path with all care (except accommodation costs) becoming free at high levels of need and at the EOL (Brown and Barker, 2014). On this point, the study provided valuable insight as it compared all types of LTCAs in old age until death. Its findings validate the Commission's view that care homes address very high health and social care needs, while

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packages of domiciliary care – provided they are accompanied by informal care, our study shows - can address medium-high health and social care needs. Hence, were the Commission's recommendations to be implemented, personal care home provision and intense packages of homecare will become free at the point of use since they cater for high care needs.

Regarding EOLC policy, the study confirms that, in England, cancer and those aged 50-64 have privileged access to hospice EOLC while those with heart conditions, COPD and age 80+ do not, albeit these latter are more prevalent at EOL than cancer or being aged 50-64. Further, EOLC in care homes is still considered suboptimal by the regulator (CQC, 2016), despite care homes being the LTC arrangement most strongly associated with dementia, the leading cause of death in all ages in the UK (ONS, 2019). This is to be linked to the differential resourcing of care homes vis-à-vis hospices, their marginalisation in EOLC policy, and their need to balance their roles as both homes and potential 'hospices'; all of which has been noted already in New Zealand (Connoly at al., 2014).

In fact, the study further reveals that care homes are becoming the *de facto* hospices for severely impaired, very old (80+) adults, affected in particular by dementia, Parkinson's disease, and stroke; who are thereby more likely (than adults in other LTC arrangements) to experience dwindling dying over many months or years. In 2016, only 6% of English care home residents died somewhere else, and in 2005 only 8% (NEoLCIN, 2017). Such a low figure is important given that in Brussels, care home death was more likely with increasing age and a noncancer diagnosis, but almost 24% of care home residents died in hospital (Houttekier et al, 2009), while in Auckland 53.5% of care home deaths occurred in the over-85s (Connoly et al., 2014).

While many scholars argue that hospice- and cancer-based models of EOLC are unsuited for dwindling and intermittent dying in very old age (Pollock and Seymour, 2018), English policy continues to fail to recognize this and the last large-scale survey of EOLC practice in

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English care homes is over 20 years old (Sidell et al., 1995). Examples of integrated EOLC planning in care homes in Australia show that care homes can reach satisfactory standards, provided their activities are backed by government funding for research and implementation (Silvester et al., 2013). Dying at age 80+ from dementia, heart conditions or COPD as well as dying in care homes thus remains a priority area for EOLC development, policy and research in England. Crucially, to study EOLC in English care homes means to study how the prevalent form of dying in the UK and increasingly in most Westernised countries (characterised by age 80+, dementia, and the severe disability and dwindling dying associated with it) can be supported and planned for.

Importantly, about 80% of older adults in our study spent the final part of their lives at home supported by family or formal carers (Table 2). Research shows that caring can be a taxing and isolating experience for relatives, especially when supporting someone with dementia (Schoenmakers et al., 2010), and that older adults living alone (as the ones in the formal LTCA were most likely to be) are more vulnerable to loneliness (Rolls et al., 2011). This indicates the need to develop a public health approach to both LTC and EOLC which builds community networks to support those living at the end of a long life and their caregivers (Gott et al., 2018).

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Fig. 1. Participants' selection criteria

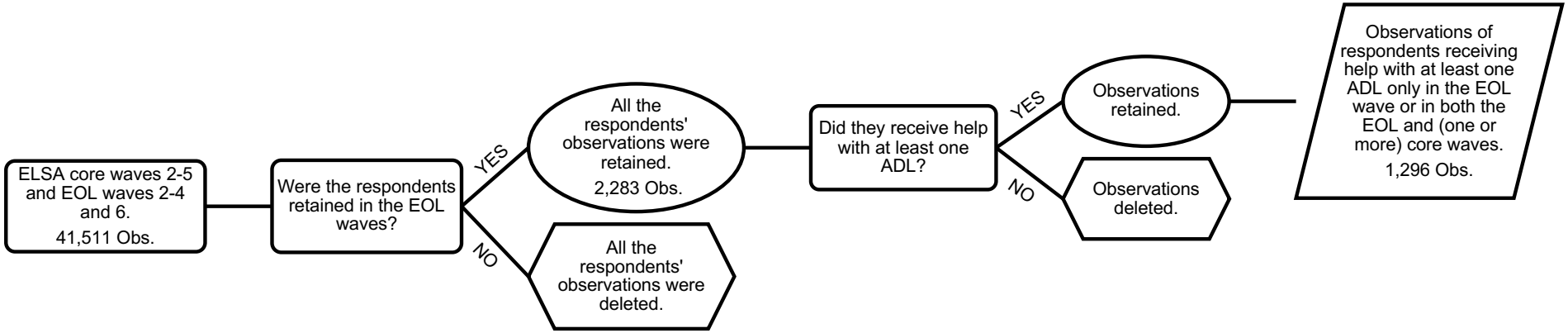

Fig. 2. Disability, Age, Dementia and Sex (AMEs)

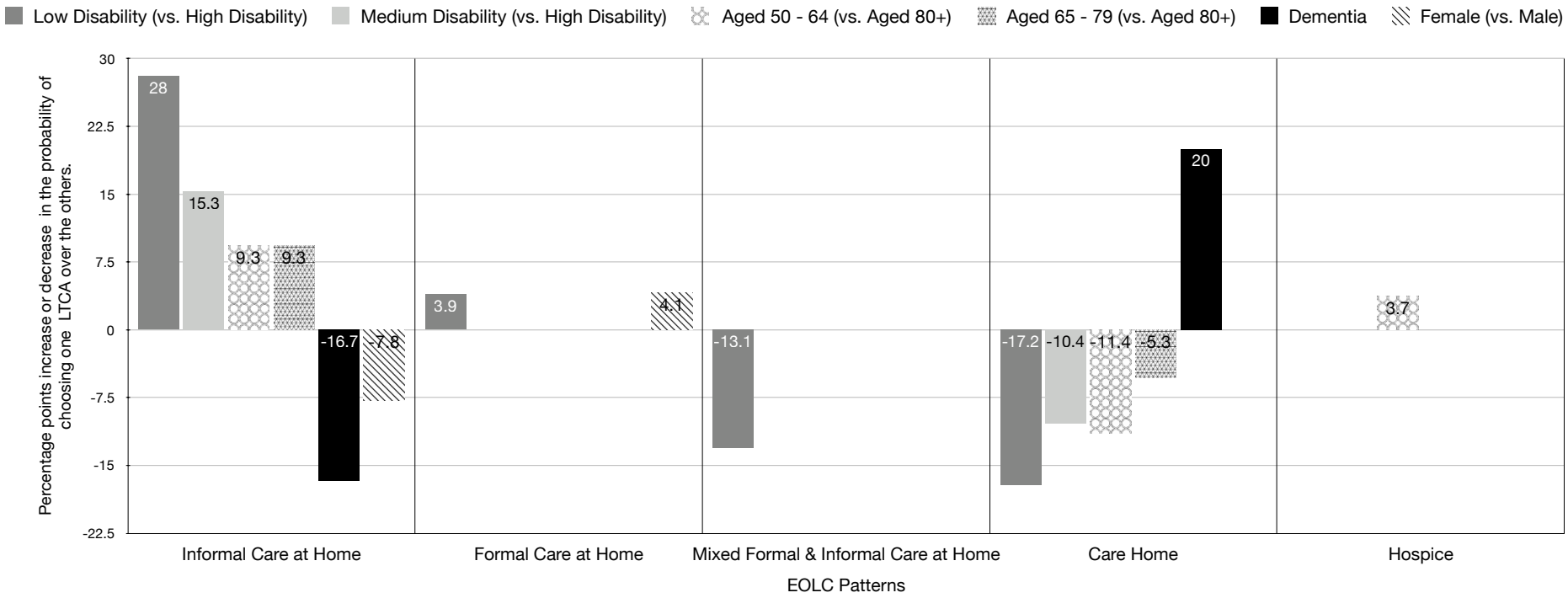

Fig. 3. Chronic Diseases (AMEs)

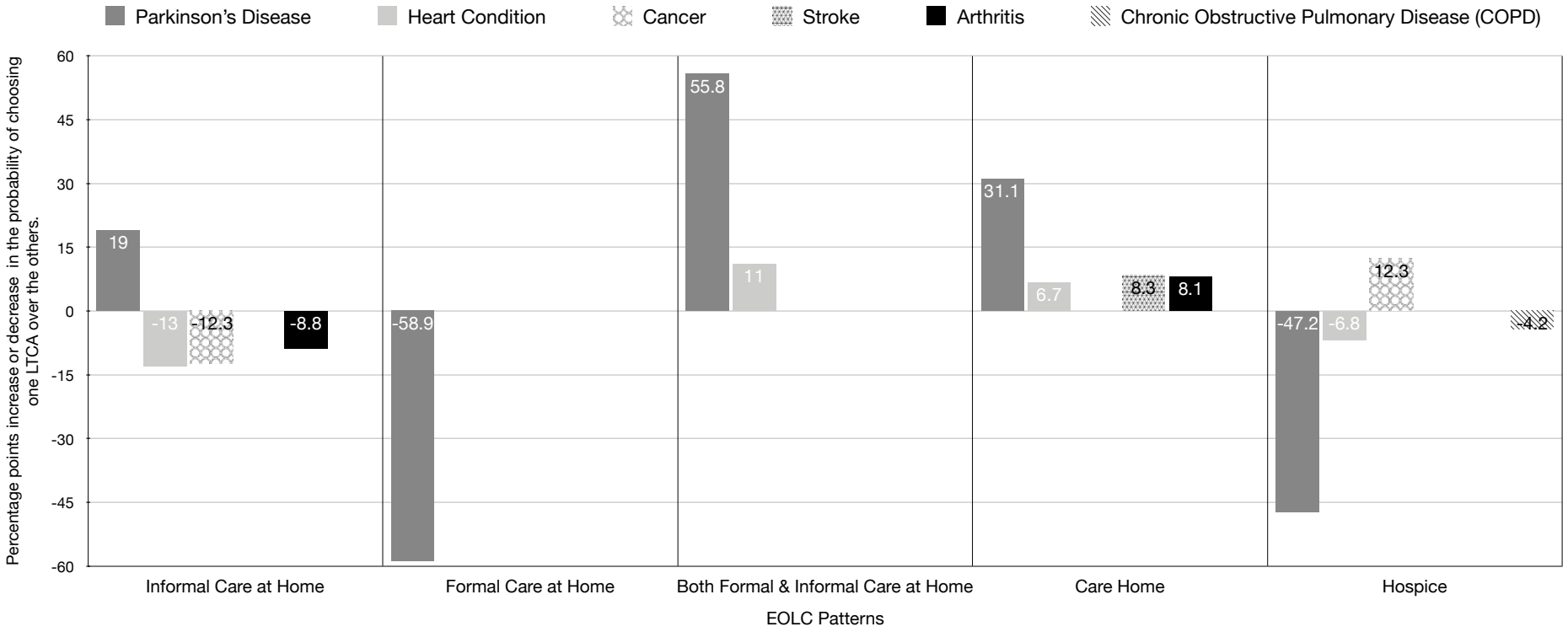

Fig. 4. Family Support and Living Arrangements (AMEs)

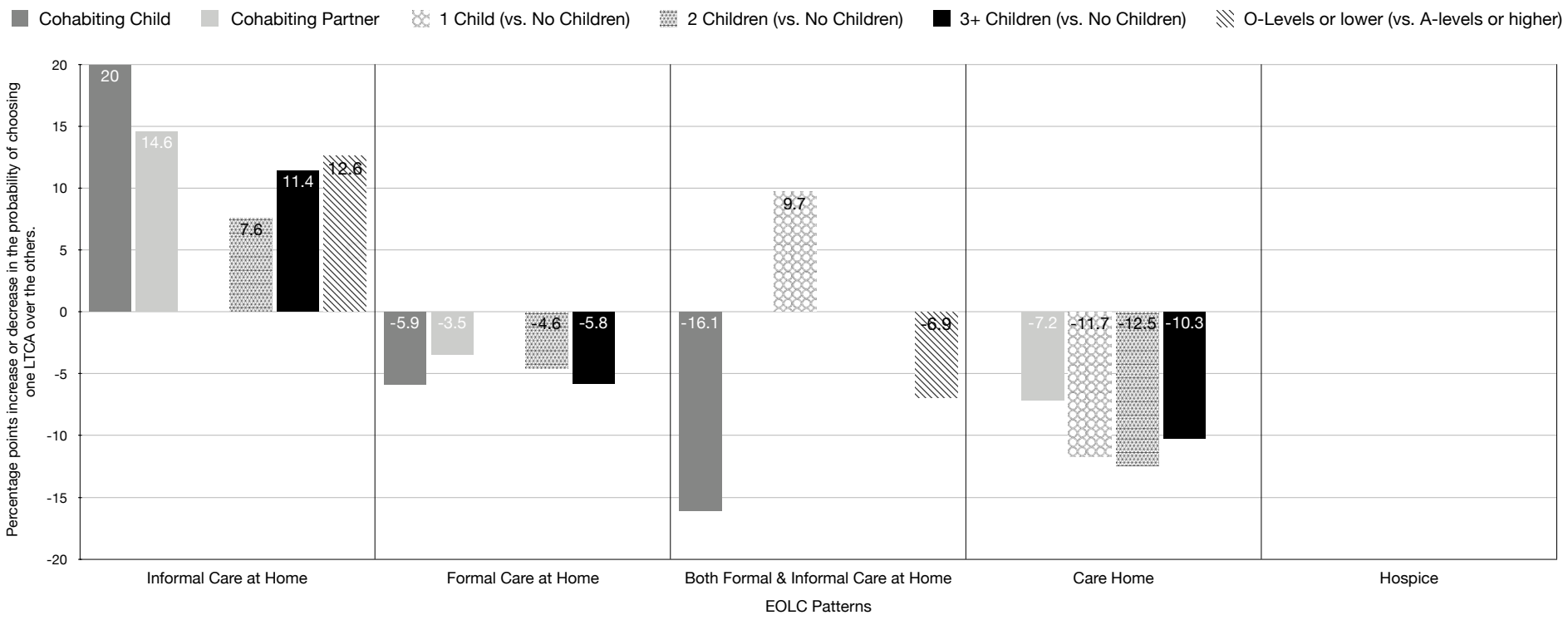

Table 1. Observational Timeframes

Timeframe	Unique Respondents	Corresponding Observations
Observed receiving LTC only when dying (in the last three months of life).	476 (60%)	476 (38%)
Observed receiving LTC from 2 years before dying to the time of dying.	203 (26%)	406 (32%)
Observed receiving LTC from 4 years before dying to the time of dying.	74 (9%)	222 (17%)
Observed receiving LTC from 6 years before dying to the time of dying.	29 (4%)	116 (9%)
Observed receiving LTC from 8 years before dying to the time of dying.	11 (1%)	55 (4%)
Total	793 (100%)	1275 (100%)

Table 2. LTC Arrangements

Arrangements	Arrangement description (who helped with the ADLs)	Percentage
Informal Care at Home	Relatives 93% (546), friends 7% (44). Tot.: 100% (590).	43.81% (557)
Formal Care at Home	Private home care workers 43% (36), local authority home care workers 34% (29)*, nurses 7% (6)*, other social or health service workers 9% (8)*, volunteers 1% (1)*, others 6% (5). Tot.: 100% (85).	5.20% (66)
Mixed Formal & Informal Care at Home	Relatives 85% (375) and friends 15% (68). Tot.: 100% (443) & Private home care workers 21% (103), local authority home care workers 49% (235)*, nurses 12% (59)*, other social or health service workers 7% (33)*, volunteers 2% (10)*, others 9% (43). Tot.: 100% (483).	30.58% (391)
Care Home / Institutional	Residential aged care facilities with and without nursing.	15.52% (198)
Hospice	Specialist palliative care, medical and social.	4.89% (63)
Total		100% (1275 Obs.)

*The categories followed by an asterisk were not specified in every wave.

Table 3. Predictors

Predictor category	Predictor	Predictor description	Sample's Percentage
	Sex	Male=0, Female=1	Male: 51.69% (659) Female: 48.31% (616)
Age	Young-Old	50 – 64 y/o	11.22% (143)
	Old-Old	65 – 79 y/o	33.73% (430)
	Oldest-Old	80+ y/o	55.06% (702)
ADLs Level The ADLs were: shopping, cooking, walking, getting dressed, bathing/showering, going in/out of bed, going to the toilet, eating, and taking medication.	Low Disability	1 to 3 ADLs	36.24% (462)
	Medium Disability	4 to 6 ADLs	28.63% (365)
	Severe Disability	7 to 9 ADLs	35.14% (448)
Main Diseases	Cancer	Diagnosed with a form of cancer.	31.29% (399)
	Heart Condition	Diagnosed with one (or more) conditions among heart attack, congestive heart failure, angina, heart murmur and arrhythmia.	54.90% (700)
	COPD	Diagnosed with chronic obstructive pulmonary disease.	19.69% (251)
	Stroke	Diagnosed with having had a stroke.	18.83% (240)
	Dementia	Diagnosed with Alzheimer's disease or another type of dementia.	15.06% (192)
	Parkinson's	Diagnosed with Parkinson's disease.	2.67% (34)
	Arthritis	Diagnosed with arthritis.	33.57% (428)
	Multimorbidity	Diagnosed with 2+ conditions among the above main diseases plus diabetes, hypertension, osteoporosis and asthma.	73.57% (938)

	Total Number of Illnesses	Number of diagnosed conditions among the same ones as in Multimorbidity.	None: 7.84% (100) One: 18.59% (237) Two: 26.04% (332) Three: 24.39% (311) Four+: 23.15% (295)
	Psychiatric Disorder		8.16% (104)
Living arrangements	Cohabiting Partner	Living with a spouse or partner.	55.15% (703)
	Cohabiting Child	Living with own adult child.	14.67% (187)
Number of respondent's adult children	No Children		15.06% (192)
	One Child		19.22% (245)
	Two Children		30.59% (390)
	3+ Children		35.13% (448)
	Income	Respondent's total income adjusted for household size.	20.00% (255) in each quantile
Education	<O-level	Less than O-level or equivalent qualification.	68.04% (668)
	O-level	O-level or equivalent qualification.	14.59% (186)
	A-level+	A-level or higher qualification.	17.33% (221)

Table 4. Multinomial Logit AMEs

Dep. Var.		Ind. Var.	dy/dx	Std. Err.	z	Sig.	96% Conf. Interval	
							Lower	Upper
Informal Care at Home								
		Sex	**-.078**	.027	-2.80	**.005**	-.132	-.023
	Age	**Young-Old**	**.093**	.043	2.16	**.031**	.008	.178
		Old-Old	**.093**	.028	3.24	**.001**	.037	.150
		Oldest-Old	Reference Category					
	ADL Level	**Low Disability**	**.280**	.027	10.13	**.000**	.226	.335
		Medium Disability	**.153**	.030	5.07	**.000**	.094	.212
		Severe Disability	Reference Category					
	Main Diseases	**Cancer**	**-.123**	.034	-3.59	**.000**	-.191	-.056
		Heart Condition	**-.130**	.033	-3.85	**.000**	-.197	-.064
		COPD	-.045	.038	-1.19	.232	-.120	.029
		Stroke	.009	.038	0.24	.814	-.067	.085
		Dementia	**-.167**	.044	-3.81	**.000**	-.253	-.081
		Parkinson's	**.190**	.086	2.21	**.027**	.021	.360
		Arthritis	**-.088**	.033	-2.63	**.008**	-.154	-.022
		Multimorbidity	.032	.018	1.75	.080	-.003	.068
		Total Number of Illnesses	.032	.018	1.75	.080	-.003	.068
		Psychiatric Disorder	-.029	.047	-0.62	.534	-.122	.063
		Cohabiting Partner	**.146**	.028	5.12	**.000**	.090	.202
		Cohabiting Child	**.200**	.043	4.57	**.000**	.114	.286
	Number of Children	No Children	Reference Category					
		One Child	.039	.045	0.87	.387	-.050	.129

		Two Children	.076	.038	1.97	**.049**	.000	.152
		3+ Children	**.114**	.038	2.94	**.003**	.038	.190
		Income	-.000	.000	-0.53	.596	-.000	.000
	Education	**<O-levels**	**.126**	.036	3.50	**.000**	.055	.198
		O-level	.069	.044	1.57	.116	-.017	.156
		A-level+	Reference Category					
Formal Care at Home								
		Sex	**.041**	.016	2.55	**.011**	.009	.073
	Age	Young-Old	.010	.022	0.44	.658	-.034	.055
		Old-Old	-.006	.017	-0.37	.711	-.041	.028
		Oldest-Old	Reference Category					
	ADL Level	**Low Disability**	**.039**	.015	2.63	**.009**	.010	.069
		Medium Disability	.018	.016	1.09	.277	-.014	.051
		Severe Disability	Reference Category					
	Main Diseases	Cancer	-.002	.016	-0. 15	.878	-.034	.029
		Heart Condition	.020	.018	1.11	.265	-.015	.056
		COPD	.020	.017	1.16	.247	-.014	.054
		Stroke	-.001	.019	-0. 06	.956	-.039	.037
		Dementia	-.007	.023	-0.34	.736	-.053	.037
		Parkinson's	**-.589**	.076	-7.73	**.000**	-.738	-.439
		Arthritis	-.000	.018	-0.01	.992	-.036	.035
		Multimorbidity	**-.050**	.020	-2.41	**.016**	-.090	-.009
		Total Number of Illnesses	.008	.008	1.00	.316	-.008	.026

		Psychiatric Disorder	-.013	.021	-0.61	.541	-.055	.028
		Cohabiting Partner	**-.035**	.016	-2.11	**.035**	-.067	-.002
		Cohabiting Child	**-.059**	.030	-1.98	**.047**	-.118	-.000
	Number of Children	No Children	Reference Category					
		One Child	-.023	.020	-1.17	.243	-.063	.016
		Two Children	**-.046**	.019	-2.45	**.014**	-.084	-.009
		3+ Children	**-.058**	.020	-2.88	**.004**	-.098	-.018
		Income	9.25e-06	.000	0.19	.852	-.000	.000
	Education	<O-level	-.024	.018	-1.34	.181	-.060	.011
		O-level	-.015	.022	-0.70	.484	-.058	.027
		A-level+	Reference Category					
Mixed Formal and Informal Care at Home								
		Sex	.031	.028	1.12	.262	-.023	.086
	Age	Young-Old	-.027	.043	-0.62	.536	-.113	.058
		Old-Old	-.052	.029	-1.76	.078	-.110	.005
		Oldest-Old	Reference Category					
	ADL Level	**Low Disability**	**-.131**	.029	-4.45	**.000**	-.189	-.073
		Medium Disability	-.050	.030	-1.68	.093	-.109	.008
		Severe Disability	Reference Category					
	Main Diseases	Cancer	-.027	.033	-083	.406	-.092	.037
		Heart Condition	**.116**	.034	3.43	**.001**	.050	.183
		COPD	.028	.037	0.74	.457	-.046	.102
		Stroke	-.054	.038	-1.41	.160	-.129	.021
		Dementia	-.020	.040	-0.50	.615	-.099	.058
		Parkinson's	**.558**	.075	7.41	**.000**	.410	.706

		Arthritis	.022	.033	0.67	.502	-.043	.088
		Multimorbidity	.030	.045	0.67	.505	-.058	.119
		Total Number of Illnesses	-.022	.019	-1.15	.250	-.060	.015
		Psychiatric Disorder	.082	.046	1.77	.077	-.008	.173
		Cohabiting Partner	-.018	.028	-0.65	.513	-.074	.037
		Cohabiting Child	**-.161**	.047	-3.39	**.001**	-.255	-.068
	Number of Children	No Children	Reference Category					
		One Child	**.097**	.046	2.09	**.036**	.006	.188
		Two Children	.074	.039	1.90	.058	-.002	.152
		3+ Children	.041	.039	1.05	.292	-.035	.118
		Income	.000	.000	0.14	.892	-.000	.000
	Education	**<O-level**	**-.069**	.032	-2.11	**.035**	-.134	-.005
		O-level	-.054	.040	-1.35	.177	-.134	.024
		A-level+	Reference Category					
Care Home								
		Sex	-.000	.021	-0.02	.985	-.042	.041
	Age	**Young-Old**	**-.114**	.043	-2.62	**.009**	-.199	-.028
		Old-Old	**-.053**	.021	-2.46	**.014**	-.096	-.010
		Oldest-Old	Reference Category					
	ADL Level	**Low Disability**	**-.172**	.023	-7.31	**.000**	-.219	-.126
		Medium Disability	**-.104**	.020	-4.96	**.000**	-.145	-.062
		Severe Disability	Reference Category					
	Main Diseases	Cancer	.030	.024	1.24	.215	-.017	.078
		Heart Condition	**.061**	.024	2.48	**.013**	.012	.110
		COPD	.039	.028	1.40	.162	-.015	.095

		Stroke	**.083**	.026	3.19	**.001**	.032	.135
		Dementia	**.200**	.021	9.15	**.000**	.157	.242
		Parkinson's	**.311**	.046	6.75	**.000**	.221	.402
		Arthritis	**.081**	.023	3.49	**.000**	.035	.127
		Multimorbidity	.038	.033	1.15	.250	-.026	.103
		Total Number of Illnesses	**-.045**	.014	-3.06	**.002**	-.074	-.016
		Psychiatric Disorder	.009	.033	0.29	.769	-.055	.075
		Cohabiting Partner	**-.072**	.020	-3.49	**.000**	-.113	-.031
		Cohabiting Child	.023	.031	0.74	.458	-.038	.085
	Number of Children	No Children	Reference Category					
		One Child	**-.117**	.030	-3.86	**.000**	-.176	-.057
		Two Children	**-.125**	.027	-4.50	**.000**	-.180	-.070
		3+ Children	**-.103**	.026	-3.90	**.000**	-.155	-.051
		Income	-.000	.000	-0.25	.800	-.000	.000
	Education	<O-level	-.016	.027	-0.60	.547	-.069	.036
		O-level	.023	.035	0. 66	.507	-.046	.093
		A-level+	Reference Category					
Hospice								
		Sex	.005	.012	0.44	.660	-.018	.029
	Age	**Young-Old**	**.037**	.018	2.05	**.041**	.001	.073
		Old-Old	.018	.014	1.30	.192	-.009	.046
		Oldest-Old	Reference Category					
	ADL Level	Low Disability	-.016	.013	-1.23	.219	-.041	.009
		Medium Disability	-.016	.013	-1.25	.212	-.043	.009
		Severe Disability	Reference Category					

	Main Diseases	**Cancer**	**.123**	.028	4.27	**.000**	.066	.179
		Heart Condition	**-.068**	.016	-4.10	**.000**	-.100	-.035
		COPD	**-.042**	.018	-2.30	**.021**	-.078	-.006
		Stroke	-.037	.022	-1.65	.098	-.082	.007
		Dementia	-.004	.022	-0.20	.843	-.047	.038
		Parkinson's	**-.472**	.050	-9.39	**.000**	-.570	-.373
		Arthritis	-.015	.016	-0.96	.337	-.047	.016
		Multimorbidity	-.018	.016	-1.07	.286	-.051	.015
		Total Number of Illnesses	**.019**	.008	2.27	**.023**	.002	.036
		Psychiatric Disorder	-.049	.025	-1.92	.054	-.099	.000
		Cohabiting Partner	-.020	.013	-1.44	.150	-.047	.007
		Cohabiting Child	-.002	.017	-0.15	.882	-.037	.032
	Number of Children	No Children	Reference Category					
		One Child	.003	.024	0.15	.877	-.044	.051
		Two Children	.021	.019	1.07	.286	-.017	.060
		3+ Children	.006	.021	0.32	.749	-.035	.049
		Income	.000	.000	1.05	.294	-.000	.000
	Education	<O-level	-.016	.013	-1.21	.225	-.043	.010
		O-level	-.022	.017	-1.30	.195	-.057	.011
		A-level+	Reference Category					

Table 5. End-of-Life vs. Open-Ended LTC

Type of LTC	Informal Care	Formal Care	Mixed Care	Care Home	Hospice	Total observations
End-of-Life LTC Care received in the last three months of life.	321 (58%)	33 (50%)	190 (49%)	148 (75%)	63 (100%)	755 (59%)
Open-Ended LTC Care received from 2 to 8 years before dying.	236 (42%)	33 (50%)	201 (51%)	50 (25%)	0 (0%)	520 (41%)
Total	557 (100%)	66 (100%)	391 (100%)	198 (100%)	63 (100%)	1275 (100%)